

Writers living with or impacted by ALS and Community Created Intervention



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BACKGROUND

I AM ALS (IAA) is a U. S. community-led nonprofit revolutionizing ALS advocacy. Community members self organize into teams around affinity groups or advocacy interests. Each team seeks to improve the quality of life of those living with and impacted by ALS and find cures and treatments for ALS. The newest team, The Write Stuff, formed as a result of community members' desire to rewrite the ALS narrative from the perspective of those living with and impacted by ALS.

RESULTS

I AM ALS' The Write Stuff has grown to 15 members. These members have published 17 posts on their website, which have attracted 395 views. Since the group formed, team members have also been published in ALS News Today and Beneath Your Beautiful. The team has also hosted one literary salon, where team members read their work aloud to an audience of 11.

METHODS

Participants agreed to form a team which meets weekly. Meetings vary, but often include guided meditations, collective writing exercises, author talks, workshops, and discussions of future writing projects. Several members have established outlets for publication, but the group also created their own website, The Write Stuff (www.alsthewritestuff.com), and works with participants to place their work.

DISCUSSION

Even when their stories are told, people living with and impacted by ALS are used to having their stories written by people who have not experienced ALS. By taking control of the narrative and writing and publishing their own accounts, people living with and impacted by ALS provide the public with new perspectives and insight into the reality of ALS as a lived experience.

REFERENCES

1. Jashelle Caga, Sharpley Hsieh, Patricia Lillo et al Front Neuro 2019, 10: 192



SCAN ME

WORDS FRM THE WRITE STUFF BLOG

"It's not easy living with ALS and even harder to travel with it."
Juan Reyes

"I'm considered dead. What an image that creates; I'm lying in a morgue with a toe tag. Dead as a doornail, six feet under. I'm deceased by definition in ALS clinical trials."

Dr. Shelly Hoover

"His dad was supposed to be the one to teach him – but his dad is no longer with us. He died, from ALS, just last December."

Elin Adcock